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On physical functioning after pediatric burns

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CHAPTER 2

How disabling are pediatric burns? Functional independence in Dutch pediatric patients with burns

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ABSTRACT

Although the attention for functional outcomes after burn injury has grown over the past decades, little is known about functional independence in performing activities of daily living in children after burn injury. Therefore, in this prospective cohort study functional independence was measured by burn care professionals with the WeeFIM® instrument in 119 pediatric patients with burns (age: 6 months–16 years; 58.8% boys) in the Netherlands. In order to identify whether functional independence was affected, participants' total scores on the WeeFIM® instrument were compared to American norm values. Of the participants assessed at 2 weeks post burn ($n = 117$), 3 months post burn ($n = 68$) and/or 6 months post burn ($n = 38$), 22, 9 and 9 participants showed affected performance, respectively. Improvements in WeeFIM® total scores for the total study population between 2 weeks and 6 months post burn were significant (Wilcoxon $T = 2.5$; $p < .001$, effect size = -0.59). Individual improvements were found to be significant for 30.3% of the assessed participants between 2 weeks and 3 months post burn, and for 12.1% between 3 and 6 months post burn. This study is unique in providing data on functional independence for this large and special population. However, a proportion of participants were lost to follow-up and the use of the WeeFIM® instrument in this specific population and setting has its limitations. To conclude, burn injury impacts functional independence in children, yet the vast majority of Dutch pediatric patients with burns returns to functional independence typical for age within 6 months post burn.

INTRODUCTION

Worldwide, millions of people get burned and many of them are children. In the United States (US) 33% of the patients with burns are under 20 years of age.¹ Young children between 0 and 4 years of age form a high risk group for burn injuries; they account for approximately 18% of all patients with burns.^{1,2} Due to improvements in burn care and treatment over the past decades attention shifted from mortality to functional outcomes. It is well known that burn injuries have a major impact on physical and psychological health. Burn injuries are often followed by an extensive period of physiological assault, pain, medication, bedrest and surgeries, which can result in a decrease in physical fitness³⁻⁵ and even continuing serious physical disability.⁶ Scarring as sequela of burns can cause itch, contractures, and (difficulties with) altered body appearance. The esthetical concerns, the traumatic nature of the burn accident and the painful wound treatments are factors that can affect psychological/psychosocial health.^{7,8} Psychopathology and psychological problems are identified in a significant minority of burn patients.⁸ Health-related quality of life remains limited throughout the first year after burn injuries in >50% of the Dutch and Flemish children with burns.⁹ Thus, children who get a burn injury during their childhood may suffer from persistent consequences throughout adolescence and adulthood.

Childhood is a very important period for development as in this period children acquire a lot of skills in several domains, like social, motor and cognitive functioning. Burn accidents are stressful life events that may cause disturbances in a child's development.¹⁰ However, the extent to which a burn injury influences the development of a child's functional independence is yet unknown. For example, burn wounds and scarring of the skin can interfere with independent performance of activities in daily living, such as ambulation, dressing and toileting. To detect risk factors for limited functioning due to burns and to enable early intervention, it is important to determine the level of actual functional independence in pediatric patients with burns.

Nowadays, the WeeFIM® instrument is widely used to assess functional independence in pediatric rehabilitation patients and children with disabilities. It has been proven to be a reliable and valid instrument in various countries: e.g. the US¹¹, Japan¹², Thailand¹³, and Turkey¹⁴; and patient groups: e.g. children with developmental disabilities¹⁵, cerebral palsy¹⁶, and spinal muscle atrophy.¹⁷ The WeeFIM® instrument evaluates the child's functional level of independence within a developmental context while requiring only a short assessment time. The instrument evaluates performance on daily living tasks in the domains of self-care, mobility and cognition. Performance is evaluated by the need for assistance from a device or helper, varying from total assistance to total independence, and is rated by certified professionals. As independence in activities of daily living increases during development, age-specific references are provided with the WeeFIM® instrument (Uniform Data System for Medical Rehabilitation [UDSMR], 2006¹⁸). The utility of the WeeFIM® instrument to describe diminished functional capacity in severely burned children aged 6–16 years was reported by Serghiou et al. (2008¹⁹). Recently, the feasibility and reliability of the WeeFIM® instrument had been established as well in Dutch pediatric burn patients; including children with minor burns and/or younger than 6 years of age.²⁰

The objective of this observational prospective cohort study is to describe the level of functional independence in pediatric patients with burns in the Netherlands measured by the WeeFIM® instrument. It aims to identify whether children aged from 6 months up to and including 16 years are affected in their functional independence at 2 weeks, 3 months and 6 months post burn, related to the child's age and the extent of the burn. Additionally, this study will indicate whether the instrument is responsive enough to detect improvement over time in this specific population and setting.

METHODS

Participants

Children were eligible for this observational prospective cohort study if they were aged from 6 months up to and including 16 years and admitted to a Dutch burn center for at least 24 h between September, 2009 and October, 2010. Patients were excluded if they had been admitted to the burn center more than 14 days post burn, if neither the child nor the parents had Dutch language proficiency and in the case that the child had previously been diagnosed mentally and/or physically disabled. In total, 86% of the eligible children from two Dutch burn centers were included²⁰, which amounted to a total of 119 participants. The medical ethical committees of the participating hospitals approved of this study.

Instrument

The WeeFIM® instrument was used to measure functional independence.¹⁸ The WeeFIM® instrument measures functional independence within a developmental context in children aged 6 months to 7 years and can be used with children over the age of 7 as long as they exhibit delays in functional abilities.¹⁸ As depicted in Table 1, the WeeFIM® instrument consists of 18 items covering three domains. For each item (task), the performance is rated on a 7-level ordinal scale. The maximum rating of 7 represents complete independence in performing the task. The minimum rating of 1 represents performance with total assistance provided by others or no performance of this task. The total score on the WeeFIM® instrument is the sum of the 18 items' scores and ranges from 18 to 126 points.

Before the WeeFIM® instrument was implemented in Dutch burn centers it was translated into Dutch and culturally adapted, as described by Niemeijer et al. (2012).²⁰ The Dutch version of UDSMR's official WeeFIM® Mastery Test had been taken and passed by all nine raters.²⁰ The translated instrument was found feasible and reliable for use in Dutch burn centers and this population of pediatric burn patients.²⁰

Dutch norm values for the WeeFIM® instrument are not available. American norm values, given as means and standard deviations, are provided with the clinical guide of the WeeFIM® instrument.¹⁸ These norm values are based on data of American children aged from 6 months till 83+ months (\approx 7+ years) with no documented developmental delay or disability and provided per interval of 3 months.

Table 1. The domains and corresponding items of the WeeFIM® instrument.

Self-care	Mobility	Cognition
Eating	Transfer – chair/wheelchair	Comprehension
Grooming	Transfer – toilet	Expression
Bathing	Transfer – tub/shower	Social interaction
Dressing – upper body	Locomotion – walk/wheelchair/crawl	Problem solving
Dressing – lower body	Locomotion – stairs	Memory
Toileting		
Bladder management		
Bowel management		

Procedure

Demographic information was registered for each participant, as well as injury characteristics like the extent of the burn. The extent of a burn is expressed in percentage total body surface area (% TBSA) involved in the burn, estimated by a burn physician. Additionally, the number of surgeries and length of stay in hospital were registered. It was also registered whether the child wore pressure garments, since this can hamper independence in dressing.

The assessments of functional independence using the WeeFIM® instrument took place at approximately 2 weeks and at approximately 3 and 6 months post burn. The assessments were done by burn care professionals (nurses, nurse practitioners, child life specialists, occupational and physical therapists) or research staff (human movement and health scientists, physicians, research nurses) working at the burn center, depending on availability. For inpatients, the assessments were done through direct observation of the child or by interviewing the child's primary care givers. For outpatients all WeeFIM® assessments were completed based on interviews taken at follow-up appointments with the nurse practitioner or burn physician. Depending on the communicative skills of the child, the information necessary for the WeeFIM® assessment was acquired from the child and/or from his/her parents.

Analyses

Identifying affected functional independence

To judge whether or not the functional independence of a Dutch pediatric patient with burn injury was affected, his/her score on the WeeFIM® instrument was equated to the American norm value specific for this child's age (in months) at the time of assessment. First, the American norm values for mean scores and standard deviations, which showed big fluctuations, were manually adapted to smooth lines. Second, those norms were complemented, carrying through the maximum scores of the 7-year-olds (ceiling) to encompass the age of 16. Third, the norm means and standard deviations were jointly plotted with the collected data against age in months. Theoretically, the number of children scoring at or below the line that represents a score of one standard deviation below the mean norm score for age, is expected to be 16% of the population ('p16'). Scores above this so-called 16th percentile line are considered as typical functional independence for age; scores at or below the 16th percentile line possibly

indicate atypical performance on daily activities. Lastly, the standard error of measurement (SEM) of 3.7 points on the WeeFIM® total scores was taken into account to determine at which point functional independence was significantly deviant from the norm ($1.96 \times \text{SEM}$).²⁰ In the present study, a child's functional independence was considered affected if his/her total score on the WeeFIM® scale (range: 18–126 points), was 8 points or more below the 16th percentile line.

Subgroups

Participants were firstly allocated to three age groups based on their age in months at first assessment. These age groups will be referred to as 'Young' (6–35 months), 'Middle' (36–83 months) and 'Older' (≥ 84 months). This grouping is related to the course of the norm values. From 6 to 35 months old the provided means show a strong rise and the standard deviations are mainly large and variable. Further, the provided norms stop at '83+' months of age; this equals the age of 7 years. From that point children are supposed to attain the maximum score on the WeeFIM® instrument.¹⁸ In addition to group for age, participants were divided into three groups based on the extent of their burn, i.e. burns involving $\leq 5\%$ TBSA, 6–10% TBSA, or $>10\%$ TBSA.

Statistics

Wilcoxon signed rank tests were applied on group results to determine improvements in functioning over time. Since children were expected to get higher WeeFIM® total scores over time, due to development and/or recovery of the burn injury, one-tailed tests were used with a significance level of 5%. Effect sizes (r) were calculated for improvement over time and interpreted according to Cohen's benchmarks: $r = .10$ represents a small change, $r = .30$ represents a medium change and $r = .5$ represents a large change.²¹ Effect size statistics have been widely recommended for use as indicators for responsiveness.²²

To determine individual change in functional independence over time the difference in WeeFIM® total score between two assessments was evaluated. The least detectable difference (LDD), calculated with the standard error of measurement and a significance level of 5%, is 11 points ($\sqrt{2} \times 1.96 \times \text{SEM}$).²⁰ A statistically significant change was therefore defined as a gain or decrease of at least 11 points (≥ 1 LDD) on the WeeFIM® total score.²⁰ The changes over time, compared to the LDD, would provide information on whether the WeeFIM® instrument is responsive in this specific setting and population.

IBM SPSS Statistics version 17 was used for analyses. Microsoft Excel was used to produce graphs. Outliers were not excluded from analyses, nor were regression or other analyses based on averaged scores used in order to preserve the information outliers could provide. Participants who were considered affected and/or who showed remarkable development over time were described.

RESULTS

Participants

The age of the 119 participants at time of admission ranged from 0 to 16 years and 70 of them (58.8%) were boys. The age group 'young' included 61.3% of the population (54.8% boys), the group 'middle' 14.3% (47.1% boys) and the group 'older' included 24.4% (76% boys). The

extent of the burns varied from 0.4% TBSA to 72% TBSA. The subgroups with extent of burn $\leq 5\%$ TBSA, 6–10% TBSA and $>10\%$ TBSA comprised 63%, 23.5% and 13.4% of the participants, respectively. Length of stay in the hospital was less than a week for more than 50% of the patients. In total, 27 of the participants (22.7%) underwent surgery, of whom 22 participants (82.1% of this selection) underwent surgery once.

Evaluation of functional independence

Group evaluations

In total, 223 WeeFIM® assessments were done for the 119 participants in this study. Of all participants 98.3% were assessed 2 weeks post burn (Fig. 1); 57.1% at 3 months post burn (Fig. 2) and 31.9% at 6 months post burn (Fig. 3). For 31 participants (26.1%) assessments were available at all three time points.

Children of similar ages showed large differences in WeeFIM® scores at 2 weeks post burn (Fig. 1). The performance of 22 children (18.5% of the total study population) was affected (Table 2). At 3 months post burn nine children (7.6% of the total study population) showed affected functional independence (Fig. 2 and Table 2). At 6 months post burn nine children (7.6% of the total study population) were affected (Fig. 3 and Table 2).

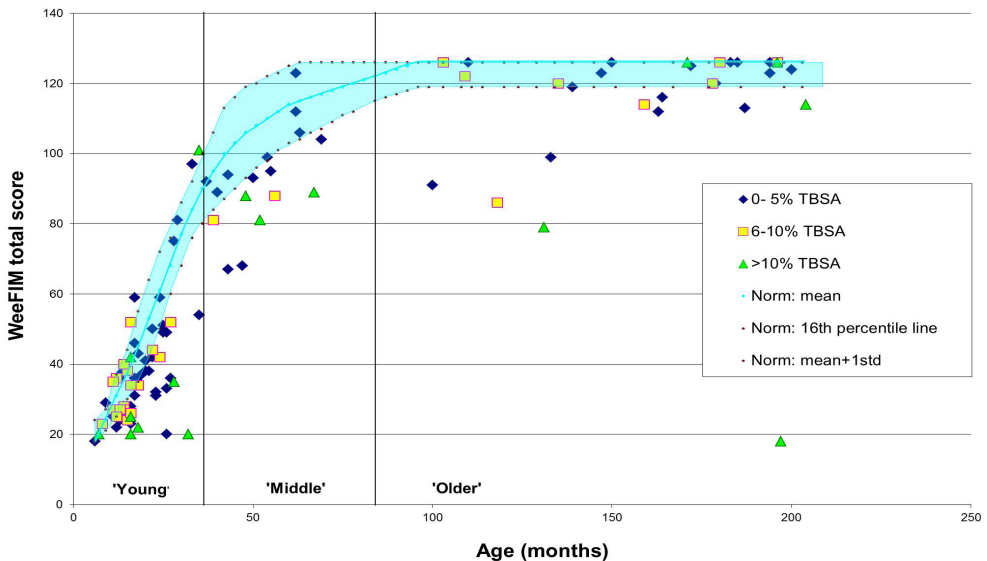


Figure 1. The WeeFIM® total scores at 2-3 weeks post burn for each participant plotted against age, displayed against the American norm values and with indications of the different subgroups based on extent of burn and age. TBSA, total body surface area; Young, 6-35 months; Middle, 36-83 months; Older, ≥84 months

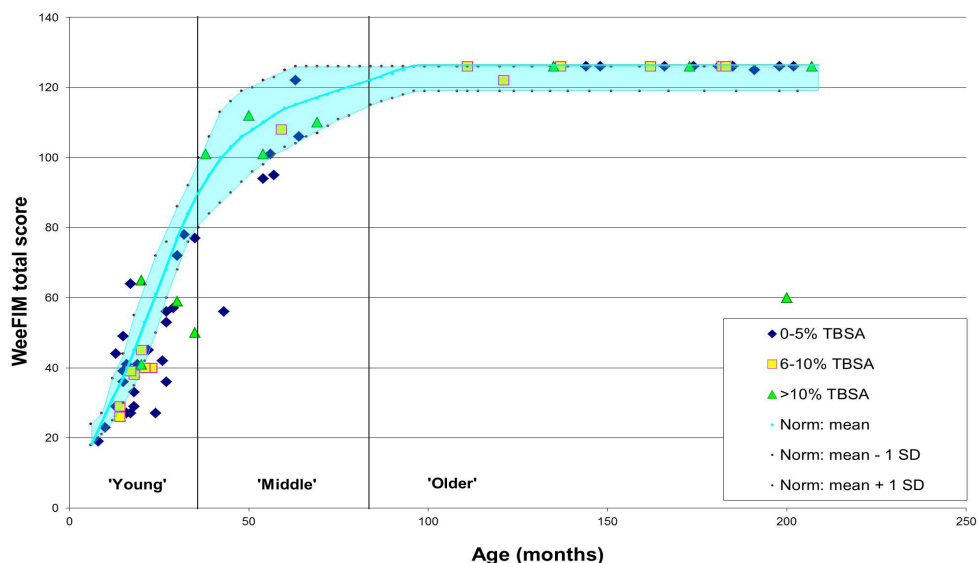


Figure 2. The WeeFIM® total scores at 3 months post burn for each participant plotted against age, displayed against the American norm values and with indications of the different subgroups based on extent of burn and age. TBSA, total body surface area; Young, 6-35 months; Middle, 36-83 months; Older, ≥84 months

Evaluation per subgroup

The 'young' children formed the largest subgroup and the variability in scores in this group was large; at first assessment scores ranged from 18 to 101 points, though at 6 months post burn scores ranged from 26 to 68. This group included the highest number of affected children at each time of assessment. The age group 'middle' comprised few children and variability in scores was smaller (range at 2 weeks: 67–123, at 6 months: 92–119). At 2 weeks post burn five children showed affected performance, against one at 6 months post burn (Table 2). In the age group 'older' five children were affected at 2 weeks post burn, of which four were still hospitalized at the time of assessment (Table 2). At 3 and 6 months all 'older' children functioned within normal limits, except for one outlier: a boy with 72% TBSA who was still hospitalized (Table 2). Scores in the group ranged from 18–126 at first assessment to 92–126 at third assessment; the lowest values were scored by this outlier.

The group with burns ≤5% TBSA included by far the highest number of children, of which the majority were part of the youngest age group. The group with 6–10% TBSA comprised the fewest affected children. In the group of children with burns >10% TBSA, eight children were affected in their functional independence at 2 weeks post burn and four children were affected at 6 months post burn. Thus, this group had a relatively higher number of affected children than the other groups.

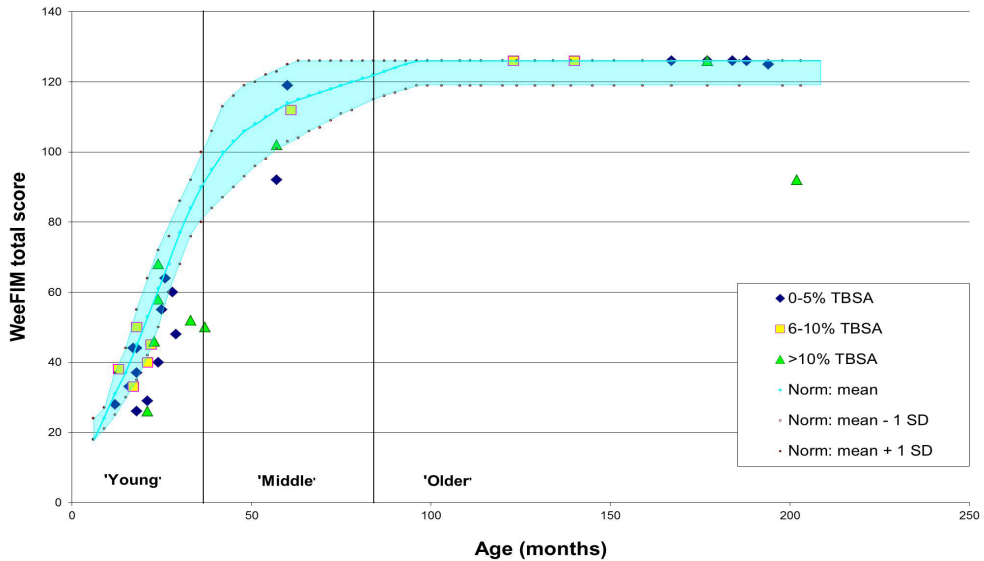


Figure 3. The WeeFIM® total scores at 6 months post burn for each participant plotted against age, displayed against the American norm values and with indications of the different subgroups based on extent of burn and age. TBSA, total body surface area; Young, 6-35 months; Middle, 36-83 months; Older, ≥84 months

Evaluation of affected subjects

To gain information on factors influencing functional independence, the cases of the 31 children (41.9% boys) that were affected at least one assessment were analyzed in detail. Of this selection, 61.3% were from the 'young' age group and 61.3% had burns involving ≤5% TBSA; these percentages were equal to those in the total population. In the selection of affected children the percentages of children with burns >10% TBSA and of those who underwent surgery were 29% and 38.7%, respectively; in the total study population these percentages were 13.4% and 22.7%. The median for length of stay in the hospital was 12 days in the affected group, while in the total study population the median was 6 days.

Four children showed affected functional independence at all three assessments. Three of them had extensive burns located at the trunk (front and back), the arms and the legs. Their ages were 2, 2 and 16 years, the burns involved 28.5%, 29% and 72% TBSA and these children underwent 1, 2 and 15 surgeries, respectively. All three had to wear pressure garments after discharge. The fourth child was a 1-year old with superficial burns involving 4% TBSA. The child was hospitalized for 16 days and did not need surgery nor pressure garments after discharge. Misinterpretation of the level of independence is not likely since the assessments were done by three different raters. On the score form the raters wrote the following remarks: "This child is from an immigrant family and culture plays an important role in her functioning. Almost everything is taken care of by the care givers, so the child is not stimulated to function independently." At the third assessment the mother told the assessor that the child functioned as he/she had done before the injury. The score for functional independence of this third assessment was significantly below the mean norm score for the child's age.

Table 2. The numbers and percentages of participants whose performance of functional independence was affected, of those who were hospitalized and of those who scored below the 16th percentile line; given per subgroups based on age and extent of burn and per assessment.

		Assessed participants				≤ 5% TSBA		6-10% TSBA		> 10% TSBA	
		<i>n</i>	<i>a</i> (%)	<i>Hosp</i>	<i>p16</i> (%)	<i>n</i>	<i>a</i>	<i>n</i>	<i>a</i>	<i>n</i>	<i>a</i>
Young	2 wk	71	12 (16.9)	9	35 (49.2)	45	8	18	0	8	4
	3 mo	38	7 (18.4)	0	21 (55.3)	26	4	7	1	5	2
	6 mo	24	7 (29.2)	0	10 (41.7)	13	4	5	0	6	3
Middle	2 wk	17	5 (29.4)	4	10 (58.8)	12	2	2	1	3	2
	3 mo	10	1 (*)	0	3 (*)	6	1	1	0	3	0
	6 mo	4	1 (*)	0	1 (*)	6	1	1	0	1	0
Older	2 wk	29	5 (17.2)	7	10 (34.5)	16	2	8	1	5	2
	3 mo	20	1 (5)	1	1 (5)	10	0	6	0	4	1
	6 mo	10	1 (*)	1	1 (*)	6	0	2	0	2	1
Total	2 wk	117	22 (18.8)	20	55 (47)	73	12	28	2	16	8
	3 mo	68	9 (13.2)	1	25 (36.8)	42	5	14	1	12	3
	6 mo	38	9 (23.7)	1	12 (31.6)	21	5	8	0	9	4

Young, 6-35 months; Middle, 36-83 months; Older, ≥84 months; wk, weeks post burn; mo, months post burn; *n*, number of assessed participants; *a*, number of affected participants within this group; *, not calculated as $n \leq 10$; hosp, number of participants hospitalized at time of assessment; p16, number and percentage of assessed participants that scored at or below 16th percentile line.

Change over time

Group analyses

The total population showed significant improvements in WeeFIM® total scores for each time interval and so did the age groups 'young' and 'older' (Table 3). The effect sizes indicate medium to large changes in WeeFIM® total scores over time (Table 3).

Individual changes between 2 weeks and 3 months post burn

Of the 66 children who were assessed at 2 weeks post burn as well as at 3 months post burn, 56 had higher WeeFIM® total scores on the second assessment (Table 4). For 20 of these 56 children (30.3%), this improvement in score was one LDD or more and therefore statistically significant. Ten children showed decreased scores at the second assessment. All ten had scored within norm values at the first assessment (Table 4). For three of these ten children the decrease was statistically significant. None of these three was hospitalized at any time of assessment, neither did they undergo surgery, nor did they wear pressure garments. Of these three, the first child – to describe here – was a 1-year old boy with burns involving 5% TBSA. He scored sufficiently at first assessment, then declined 15 points at second assessment, and returned to non-affected performance at third assessment. The second child was a 3-year old girl suffering burns of 3% TBSA. Her performance was non-affected at first assessment, but

Table 3. Improvement in WeeFIM® total scores between assessments, given per age group.

	2 weeks – 3 months			3 months – 6 months			2 weeks – 6 months		
	<i>T</i>	<i>p</i>	<i>r</i>	<i>T</i>	<i>p</i>	<i>r</i>	<i>T</i>	<i>p</i>	<i>r</i>
Young	111.5	<.001	-.38	27.0	.010	-.38	0.0	<.001	-.62
Middle	9.5	.117	-.27	2.0	.137	-.39	1.0	.072	-.52
Older	0.0	<.001	-.56	0.0	.090	-.30	0.0	.009	-.53
Total	228.5	<.001	-.42	41.0	.002	-.36	2.5	<.001	-.59

T, test value for Wilcoxon Signed Rank Test; *p*, one-tailed significance value; *r*, effect size

with a decrease of 33 points her performance was affected at second assessment. There were no remarks and the girl was not assessed at 6 months post burn. The third child was a 1-year old boy with a burn involving 1% TBSA who scored 13 points above his norm value at first assessment. Despite the fact that his score declined 20 points at second assessment, it remained within normal limits. He was not assessed at 6 months post burn. Overall, scores of most children changed less than one LDD. The majority of children maintained non-affected scores or changed to scoring within normal limits for age between 2 weeks and 3 months post burn.

Individual changes between 3 months and 6 months post burn

Of the 33 children who were assessed at 3 months post burn as well as at 6 months post burn, 29 had higher scores on the last assessment, of which four (12.1%) improved one LDD or more (Table 5). None of the four decreases in scores was 1 LDD or more. Although individual scores changed over time, performance status did not change for most children: their scores remained either non-affected or affected.

Table 4. Change in WeeFIM® total scores and change in performance status between 2 weeks post burn and 3 months post burn.

	Stays nonaffected	Affected to nonaffected	Stays affected	Nonaffected to affected	Total
Improvement					
< 1 LDD	35	0	0	1	36
≥ 1 LDD	9	7	4	0	20
Decrease					
< 1 LDD	6	0	0	1	7
≥ 1 LDD	1	0	0	2	3
Total	51	7	4	4	66

Affected, total score ≥8 points below 16th percentile line; LDD, least detectable difference.
Changes ≥1 LDD are significant

Table 5. Change in WeeFIM® total scores and change in performance status between 3 months post burn and 6 months post burn.

	Stays nonaffected	Affected to nonaffected	Stays affected	Nonaffected to affected	Total
Improvement					
< 1 LDD	21	0	2	2	25
≥ 1 LDD	2	1	1	0	4
Decrease					
< 1 LDD	1	0	1	2	4
≥ 1 LDD	0	0	0	0	0
Total	24	1	4	4	33

Affected, total score ≥8 points below 16th percentile line; LDD, least detectable difference.
Changes ≥1 LDD are significant

DISCUSSION

Burns impact the functional independence in Dutch pediatric patients with burns. At 2 weeks post burn about one-fifth of the participants showed affected functional independence, as measured by the WeeFIM® instrument and compared to American norm values. Fortunately, the majority of the children returned to functional independence adequate for age within 3 months and only few children showed affected performance at 3 and 6 months post burn. This indicates recovery within six months post burn, which proves that 6 months is an appropriate time span for follow-up in this population. This is in line with findings by Serghiou et al. (2008)¹⁹, who reported that children from 6 to 16 years old with burns up to 15% TBSA attained maximum improvement in functional independence about 6 months post burn.¹⁹ Gorga et al. (1999) reported age-appropriate independence in self-care skills in children (aged 6 months–6 years; TBSA range 1–20%) at 1, 6 and 12 months post burn and found significant improvements in motor skills over time.¹⁰

About one-third of the participants in the present study significantly improved on the WeeFIM® total score within 3 months post burn. This indicates that the WeeFIM® instrument is responsive enough to detect changes in Dutch children with burns, regardless of their age or extent of the burn. Furthermore, the effect sizes found in this study represent medium to large responsiveness.²²

The children younger than 3 years of age showed a lot of variability in scores and a higher rate of affected participants at follow-up assessments than older children. Note that this subgroup formed a big part of the total group of children admitted to Dutch burn centers and therefore strongly influenced the general results.

Utility of the WeeFIM® instrument

In a Dutch pediatric population

Overall, few participants were considered affected, according to the definition in this study. Nonetheless, many scores were below the mean norm scores, mainly for the young children. A first possible explanation for this is that American norm values would differ from Dutch standards. Next to personal, social and environmental factors, culture plays a role in differences in skill development. Differences in functional independence measured by the WeeFIM® instrument that are due to culture were mentioned before.^{13,23} Cross-cultural validation of the WeeFIM® instrument has not been done yet for northern European countries, but it was done for the Pediatric Evaluation of Disability Inventory (PEDI). The PEDI was developed as both an assessment and evaluative tool for children with disabilities from 6 months to 7.5 years of age. It measures ability related to self-care, mobility and social function and it is used to give functional descriptions. The PEDI shows a strong correlation with the WeeFIM® instrument, indicating that these instruments measure similar constructs.²⁴ Berg, Aamodt, Stanghelle, Krumlinde-Sundholm, and Hussain (2008) showed that a randomized Norwegian population scored, for both functional skills and caregiver assistance scales, significantly worse than the American norm group in the domains of self-care and mobility and somewhat lower for social function.²⁵ PEDI score profiles of Dutch children ($n = 20$; age range: 23–86 months) were also found not to be compatible with those of American children, although self-care and mobility seemed cross-culturally similar in this very small sample.²⁶ For the WeeFIM® instrument, Dutch normative values for children younger than 3 years would probably be below American values.

Secondly, the large variability in scores and many below the norm values in the group of children younger than 3 years, could suggest that the WeeFIM® instrument might be less suitable to assess functional independence in children this young. In an informal evaluation our raters reported that they experienced difficulties in scoring children aged 2 and 3 years. Serghiou et al. (2008) had reported difficulties scoring young children with burns as well.¹⁹ They discovered that the levels of independence in the young age group in their study (6 months to 6 years) were misinterpreted by the raters, forcing them to disregard these data. This having happened had made us extra alert to this potential problem. The current data do not indicate misinterpretations as described by Serghiou et al. (2008). The inter-rater reliability between raters in the current study was good in children younger than 7 years ($ICC = 0.989$), although it was lower than in the total study sample that comprised children up to and including 16 years ($ICC = 0.996$).²⁰ To prevent scoring difficulties in young children, in future research the 'WeeFIM® Instrument: 0–3 Module' could be used.²⁷ This instrument, consisting of 36 items rated on a 3-level scale, was developed to measure precursors to basic daily living function in young infants, but was not yet available at the start of this study.

For children older than 3 years, on the other hand, the WeeFIM® scores found in this study were reasonably similar to the American norm values. This implies (1) that these children's level of functional independence is adequate for their age and (2) that obtaining Dutch norm values would not be necessary. For older children with burns (7+ years) however, the WeeFIM® instrument might have a ceiling effect. In this study all children over 7 are functioning well

from 3 months post burn on, except for one outlier with 72% TBSA. The instrument measures if a child's functional independence is sufficient for a 7-year old, but will not differentiate between different levels of independent functioning matching the individual age of the subject older than 7.

In children with burns

The WeeFIM® instrument has been proven to be a feasible and reliable measure for use in the Dutch burn centers and the population of children with burn injury. There are, however, also some drawbacks to the use of the WeeFIM® instrument and the interpretation of the results in this population and setting. Firstly, hospitalization could restrict WeeFIM® scores on each domain, because the WeeFIM® measures actual performance and not ability. For example, even if the child would have been capable of it, dressing could not be accomplished (domain self-care), walking stairs was impossible as there were no stairs in the burn center (domain mobility) and social interaction with peers was impossible because of isolated rooms or simply absence of peers (domain cognition). So, even on tasks which were not assumed to be directly affected by a burn, performance could be below the child's actual ability. A strong improvement in scores could be obtained due to discharge from hospital. Secondly, the time between surgeries and assessment should be kept in mind. Even though few of the participants in this study underwent surgery, it is a relevant factor for patients with burns that can influence functioning. Thirdly, some children had to wear pressure garments, which are tailor-made and very tight. It is impossible to get into or out of those pressure garments without assistance and this may have limited scores on dressing items.

Overall, we feel that the WeeFIM® instrument can certainly give a relevant indication on a patient's (difficulties in) functional independence, but that the abovementioned remarks should be taken into account in case of implementation of the WeeFIM® instrument in clinical practice or reproduction of the study.

Limitations in study design and conduct

A reasonable amount of participants was lost to follow-up at 3 months post burn and even more at 6 months post burn. The reason is that children who showed good recovery did not need follow-up visits at the outpatient clinic and therefore were not assessed anymore. This caused a slight selection bias at 3 and 6 months post burn; only the subjects that were still experiencing problems related to their burn injury returned for follow-up assessments. This might suggest that the population was doing even better than shown by the collected data. Besides this systematical bias, a small minority of children was randomly missed for assessment due to practical reasons (e.g. unavailability of rater, no follow-up visit planned at assessment time point).

Study strengths

First, this study is unique for its follow-up on functional independence in this large and special population. Second, as no selections were made on inclusion of participants, the study population forms a good representation of Dutch pediatric patients with burns. Third, all participants were assessed by certified raters. Fourth, the scores of each assessment were compared to norm scores determined for the participants' exact age at that assessment.

Functional independence; the end result

The majority of Dutch pediatric patients with burns returns to functional independence typical for age within 6 months post burn. At 6 months post burn only nine children showed affected functional independence, which is 7.6% of the total study population. In the light of issues discussed above, though, some remarks can be placed. Of those nine children, four were affected at all assessments. For one of those four it was reported that the deviance from typical functioning was not due to burn injury, but to cultural influence. The other three had extensive burns and underwent surgery. One of them was even still hospitalized at time of third assessment and all wore pressure garments after discharge; both factors that restrict independence.

Of the other five from these nine affected participants at 6 months post burn, four had shown non-affected functional independence earlier. Their scores decreased between second and third assessment, but these decreases were not statistically significant. The fifth child had just not been assessed at 3 months post burn.

Furthermore, it must be noted that of the nine children, seven were from the youngest age group (<3 years). As mentioned before, children in this age were experienced as difficult to rate and furthermore the WeeFIM® instrument and American norm values might not be appropriate for Dutch children this young.

The abovementioned remarks nuance our finding that nine children remain affected in their functional independence. Overall, we feel that functional independence is adequate in children 6 months after burn injury.

Future research

The WeeFIM® instrument has not been implemented in standard care in the Dutch burn centers. If subsequent research is intended at a large scale, Dutch norm values should be obtained and the 'WeeFIM: 0–3 Module' should be applied for young infants.

It was felt by the burn care professionals that psychosocial factors could play a role after discharge, e.g. the child could ask for more assistance than necessary or the parents could get overprotective as a result of the burn accident. For additional research it would be interesting to link the acquired WeeFIM® scores to data on the psychosocial functioning of the children and their parents, in order to explore relationships with the independence of the child.

Conclusions

The WeeFIM® instrument was found to be responsive enough to detect improvement over time in the functional independence of children with burns.

Functional independence was affected in 22 (out of 117) Dutch pediatric patients with burns at 2 weeks post burn, in nine children (out of 68) at 3 months post burn and in nine children (out of 38) at 6 months post burn. Concerning age, the group of children younger than 3 years accounted for the most affected children at each time of assessment. Concerning the extent of burn, the subgroup of children with burns involving >10% TBSA had a relatively higher number of affected children than the other groups.

Concluding, burn injury impacts children's functional independence. Fortunately, after 3 months functional independence is adequate in most children with burns.

Disclaimer

The use of the WeeFIM® instrument to collect data for this research study was authorized and conducted in accordance with the terms of a special purpose license granted to Licensee by Uniform Data System for Medical Rehabilitation, a division of U B Foundation Activities, Inc. ("UDSMR"). Licensee has not been trained by UDSMR in the use of the WeeFIM® instrument, and the patient data collected during the course of this research study have not been submitted to or processed by UDSMR. No implication is intended that such data have been or will be subjected to UDSMR's standard data processing procedures or that it is otherwise comparable to data processed by UDSMR.

Conflict of interest

The authors declare that there are no conflicts of interest.

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